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GOVERNOR'S COMMISSION ON MENTAL RETARDATION

Strategies for Reducing the Waiting List for Services from the Department of Mental Retardation in Massachusetts

Report to Governor William F. Weld

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*Report from the Commission's first public hearing held
Tuesday, June 28th, 1994 in the Gardner Auditorium of the
State House.*

Report to Governor William F. Weld

Strategies for Reducing the Waiting List for Services from the Department of Mental Retardation in Massachusetts

The Commonwealth of Massachusetts

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I. INTRODUCTION

"These parents are living on the brink of disaster every day of their lives. They are living in absolute fear of what will happen to their mentally retarded sons and daughters when, for reason of sickness or death, they as parents are no longer able to care for their child." John Learnard, parent, Board member, Charles River Arc, Needham, MA.

One of the most compelling public policy issues facing the Massachusetts mental retardation services system today is the growing numbers of individuals and their families who have either very limited or no access to the services system. Individuals and their families who are waiting for services was identified as a top priority by the Governor's Commission on Mental Retardation. The Commission's concerns, however, extend beyond the sheer volume of persons with mental retardation who are either unserved or underserved and also focus on how and when the Commonwealth can eliminate this list.

As created by Executive Order 356, the Governor's Commission on Mental Retardation is mandated to hold at least two public hearings annually. The purpose of these hearings is to highlight, among other issues, the extent to which the mental retardation services system provides opportunities for persons with mental retardation. Accordingly, the first public hearing scheduled by the Commission was devoted to identifying strategies that address those persons with mental retardation and their families waiting for services.

Both oral and written testimony was solicited from hundreds of individuals with mental retardation and other disabilities, family members, providers, advocates, public officials, legislators and others. The hearing was held on Tuesday, June 28, 1994 at the Gardner Auditorium in the State House in Boston. A total of 39 individuals presented oral testimony and another 40 submitted written testimony. One hundred thirty-nine (139) individuals attended the hearing.

This report highlights the complexities of the waiting list issue in four major sections:

- A national overview of waiting list issues,
- An analysis of the Department of Mental Retardation's waiting list data and a description of its eligibility process,
- A summary of the major themes expressed at the public hearing as illustrated by individual testimonies, and
- A list of specific recommendations directed at various aspects of the mental retardation and human services system.

It should be noted that it is difficult to focus on waiting list issues without also considering the quality of services to which people on the waiting list are seeking access. The Governor's Commission on Mental Retardation is concerned with both the access to services issues (the subject of this report) and the quality of services provided in the Commonwealth to persons with disabilities (the subject of future reports). Indeed, much of the testimony presented to the Governor's Commission during the public hearing focused on the types of services needed by individuals who are currently unserved or underserved by public agencies with a mandate to provide services to eligible citizens.

The range of services desired and needed is diverse. For some, the call is for more tailored, individualized, and responsive services that support the widespread efforts of families to provide loving, decent, and dependable care for their family members with mental retardation. For some, the call is for more innovative publicly supported residential options that enable individuals with mental retardation to remain in their communities in supervised homes. For some, the call is for greater stability in the complex web of community-based services programs, a plea that has at its base the recognition that increased compensation for community-based providers is a prerequisite to needed stabilization. For some, the call is for smoother interfaces among the diverse agencies to insure that relevant services are coordinated and easier to access. All of the earnest concerns warrant consideration and immediate action.

It also bears noting that for persons with mental retardation, the service systems that support them are essentially long-term care systems. It is rare for a person with mental retardation to "exit" from the service system once they have gained access. Because mental retardation is not an episodic condition, the services that provide basic support to individuals -- income maintenance, housing, transportation, employment, social/recreational, and therapeutic interventions -- are expected to be durable and available over time. For the thousands of individuals who reside with their families, the constellation of family support services -- direct cash subsidies, respite care, and counseling -- are critical components to their caregiving efforts.

Based on the testimony received by the Governor's Commission on Mental Retardation, it is clear that there is no "single template" for the service menu that is desired and needed by persons with mental retardation and/or their families who are currently unserved or underserved by relevant public service agencies. This fact is important to keep in mind -- namely, we must recognize that individual goals differ and that utilization of publicly supported services must be determined one person at a time. Herein lies the potential creativity of public service agencies. This report is dedicated to the spirit of innovation and commitment that characterizes the best of public servants and the agencies for which they work.

II. NATIONAL PERSPECTIVES ON WAITING LIST ISSUES

Information concerning the number of persons with mental retardation waiting for services across the country and the strategies used by other states to address this issue was obtained from four sources:

- The Center on Residential Services and Community Living at the University of Minnesota,
- The Commission's national survey,
- State waiting list reports, and
- Testimony provided by Robert Gettings, Executive Director of the National Association of State Directors of Developmental Disabilities Agencies.

The Center on Residential Services and Community Living, University of Minnesota

One of the few comforts that Massachusetts can find in addressing the needs of thousands of persons with mental retardation waiting for services is that it is not alone. Recent studies highlight that the growing demand for community based services and waiting lists have become a common reality for most state agencies (Davis, 1987; Hayden, 1992; Smull, 1989). In 1992, the Center on Residential Services and Community Living at the University of Minnesota published the results of the most comprehensive analysis of national waiting list information to date. After adjusting the reported numbers for duplicate counting and non-responding states, the Center's staff concluded that the total number of services being waited for by people with developmental disabilities was approximately 182,000. Residential services accounted for the largest need (33%) followed by day habilitation or vocational services (19%) and other support services (18%) (Hayden, 1992).

The University of Minnesota has updated the numbers of persons waiting for residential services. They report that *on June 30, 1993, an estimated national total of 78,700 persons were waiting for residential services*. They determined that the U.S. residential services system would need a 20.3% growth in capacity to meet the current need. There was, notably, considerable national variation in the

needed growth in community residential services. For example, five states (**California, Idaho, Maryland, North Dakota and Rhode Island**) reported to not have any persons with mental retardation waiting for residential services. Four states (**New York, Kentucky, North Carolina, and Oregon**), however, had such long waiting lists for residential services that they would need to expand their service systems by one-third to accommodate presently identified needs (Managan, Blake, Prouty & Lakin, 1994, p. 36).

Managan, Blake, Prouty & Lakin's analysis determine that based on 1991/92 data, Massachusetts would need to expand its residential service system by 14% to meet the needs of persons on the residential waiting list. In comparison, this magnitude is less than some of its New England neighbors (Connecticut needs to expand by 19%) but more than others like Vermont (11.9%), New Hampshire (4.6%) or Rhode Island (0%), which reports no waiting list for community residential services.

The Commission's National Survey on Waiting List Strategies

In June 1994, the Governor's Commission staff mailed a survey to the directors/commissioners of mental retardation/developmental disabilities agencies in 53 states and territories (excluding Massachusetts). The types of data requested included the following:

- If the state has a waiting list,
- Numbers of individuals with mental retardation waiting for services,
- The types and effectiveness of strategies used to address waiting list issues, and
- If the state has a written plan addressing waiting list issues.

Thirty-nine states and the District of Columbia responded to the survey (77% response rate). Of the 40 respondents, 34 states noted that they currently maintain waiting lists for services or supports for persons with mental retardation or related developmental disabilities (many of the states use "developmental disabilities" to define eligibility for services). Although four states indicated that they maintained waiting lists, information was kept at the local/area office or on a program basis

and was not aggregated statewide. Another six states reportedly did not maintain lists of persons waiting for services.

Thirty-two states described a variety of strategies that have been implemented to address waiting list issues. In descending order, the most common strategies used were:

- Securing additional revenues, primarily through the Medicaid Home and Community Based (HCB) waiver and other grants (27 states),
- Securing additional state revenues (23 states),
- Developing partnerships with families (e.g., expanded family support options) and/or other private entities (17 states),
- Developing innovative housing and/or day/employment strategies (16 states)
- Convening a task force or planning committee specifically focused on waiting list concerns (12 states)
- Redefining service eligibility and adopting regulatory reforms (4 states), and
- Other strategies such as individualizing services, implementing a priority system, developing a "fee for service" program, and creating a computer network between agencies to show who is in "interim" services but still awaiting "optimum" service (7 states).

State Waiting List Reports

The Commission also requested copies of state reports which included information on waiting list issues. Five reports were received. Below, key points from these reports are described.

- **Acquisition of Better Information: Using Data to Clarify the Needs of Persons Waiting for Services.**

Four states focused on obtaining better information on individuals with mental retardation waiting for services. In its five-year plan (FY '93-'94 to FY '97-'98), the **Alabama** Division of Mental Retardation states that it is in the process of verifying its waiting list and will update its plan to reflect the needs of individuals

who have applied for services. Reorganized local community boards in Alabama eventually will have responsibility for waiting-list verification, since they will be the single point of coordination for mental retardation services (Alabama Division of Mental Retardation, Five-Year Plan, 1993).

Other states either have implemented or are proposing to implement more careful analyses of their waiting lists. For example, the **New York** Office of Mental Retardation & Developmental Disabilities recently conducted an "outreach campaign" to update its existing needs information form and to identify the unmet needs of individuals and families not currently registered in its data base. As highlighted in its 1990-1995 year plan, the initial phase of this needs assessment project identified 5,600 persons by name in the community who were in need of immediate residential placement. An additional 2,000 persons living at home were in need of day services within the current fiscal year, and another 7,600 people were in need of a family support service. It is not known, however, how many of these individuals were already in the State's data base, and how many were "new" cases identified through the needs assessment project. In response to the Commission's June 1994 survey, New York estimated that 33,822 people with mental retardation are waiting for services.

New York officials are analyzing the increasing demand for services in the context of other system pressures -- facility phase down and closure and litigation requirements -- and are proposing a variety of strategies, such as developing partnerships with individuals with mental retardation and their families, to address unmet needs in a planful way. (New York Office of Mental Retardation and Developmental Disabilities, The Community Challenge: NY DD Plan 1990-1995, Executive Summary, 1993).

In **Connecticut**, a "waiting list planning committee" recently recommended that the Department of Mental Retardation develop and conduct a survey to identify the actual and true needs of all persons on the waiting lists and extend it to people who potentially could be on the lists. The survey would not be limited to existing services of only residential or day services but would also encourage individuals and families to describe whatever creative support options they feel would meet their needs. Further, the survey results would be used to develop a "planning list" by distinguishing between persons who need to be served

immediately and those who want to plan ahead for future services (Connecticut Waiting List Planning Committee, Planning Report to Eliminate the DMR Waiting Lists, February 7, 1994).

Finally, the **Colorado Developmental Disabilities Council** recently funded a private organization to gain a more accurate understanding of the nature of the waiting list. The specific goals of the study were: (1) to verify the waiting list information for persons with developmental disabilities who are waiting for residential and day services by type of service and (2) to gather information from individuals with disabilities and/or their family members/guardians in their own words, on the services and supports they believe will best meet their needs. A sample of 513 individuals with developmental disabilities were selected from the target population and respondents were asked a variety of questions including the length of time that had passed since they were scheduled to have received services (Colorado Developmental Disabilities Planning Council, A Study...Colorado's Waiting List for Developmental Disability Services, July, 1993).

- **Funding Strategies: A Tale of Two States**

As part of a series of short-term strategies to help eliminate its waiting list, **Connecticut's DMR** has proposed implementing three pilot programs in 1994-1995: (1) a multi-regional focus for 150 individuals who are unserved and have a wide range of needs, (2) a project to either convert or redirect existing funding for approximately 190 individuals who are in privately funded community living arrangements and who want to move to less supported settings, and (3) a project for individuals in the public sector by obtaining a Medicaid waiver to serve approximately 50 people from Southbury Training School who want to move into the community.

Connecticut is one of the 27 states that is relying on its Medicaid HCB waiver, and specifically the ability to obtain retained revenues, as a funding strategy to address waiting list issues. As the report's authors note: *"We recommend that any new federal reimbursements from DMR that come into Connecticut should go into a dedicated account for DMR to fund supports and services to individuals on the waiting list. In other words, new federally matched dollars generated by DMR are recommended to come directly back to DMR rather*

than going to the General Fund. In this way, funds are earmarked for use by persons with mental retardation who are currently unserved. Any new waiver reimbursements are recommended to be used to fund individuals on waiting lists. (Connecticut Waiting List Planning Committee, Planning Report to Eliminate the DMR Waiting Lists, p. 22).

Funding strategies using both public and private resources dominate **Florida's** 1994-1996 strategic plan update and are presented in five major categories: expanding resources, redirecting resources, increasing the use of non-funded supports, making more effective use of current resources and developing alternatives to create greater equity in distribution and use of state resources -- all of which will be used to maximize the number of people served (Florida Department of Health and Rehabilitative Services, Living Everyday Lives: Update-Strategic Plan for Individuals Who Have Developmental Disabilities, 1994-1996, 1994).

- **Planning Activities: The Pursuit of Data**

Seven states reported some type of planning activity directed at waiting list issues (Alabama, Connecticut, Florida, Kansas, New York, Pennsylvania, and Washington in process). **Florida, Alabama, and New York** have addressed waiting list issues as part of their overall strategic plans for statewide mental retardation services, while Connecticut and Kansas produced specific planning documents on waiting list concerns.

Within their planning documents, both **Connecticut** and **Kansas** developed cost estimates based on a systematic analysis of waiting list information. While Connecticut has proposed moving its entire services system to person-centered funding, Kansas has developed a five-tiered reimbursement system. The Kansas Commission on Mental Health and Retardation Services (MH/RS) assigns rates based on certain cost data assumptions developed by the accounting firm of Deloitte and Touche. These costs are determined by the relative severity of the individual's disability. Based on this information, the Kansas MH/RS estimates that it will need approximately \$11,600,000 to provide services to everyone currently requesting immediate services through their local community MR/DD agencies.

The Kansas report stresses that *"in spite of vigorous efforts to expand services, the waiting list has not declined appreciably in the last several years."* The report's authors note, however, that the current process may not provide valid indicators of who, among the 3,554 people with MR/DD and their families currently unserved in Kansas, will need immediate services and the approximate cost of these services. *"If the waiting list is to maintain its credibility as a measure of future need, more research must be done to better predict future waiting list needs."* (Kansas MH/RS, Department of Social and Rehabilitation Services, A Preliminary Report on Kansans Who Are Mentally Retarded or Otherwise Developmentally Disabled Waiting for Community Services, August, 1993, p. 7).

Indiana's legislature recently created an MR/DD Commission which is charged with developing a planning process for the state that will address, among other things, how to meet the needs of individuals and families waiting for services. The **Indiana Collaboration Project** also was initiated to identify needs for all types of human and social services at the local level in order to reduce fragmentation and to maximize resources through refinancing and capturing additional federally matched dollars.

As illustrated above, states have pursued several types of strategies that focus on waiting list concerns. Some of these strategies have been more effective than others. Thirty-five states indicated to us the degree of effectiveness for various strategies. The most effective strategies in order of importance are as follows:

- Obtaining additional federal or state revenues,
- Developing strong working relationships with state budget bureaus, legislators, and advocacy groups,
- Prioritizing services for certain groups (e.g., individuals with care givers over 65),
- Obtaining increased flexibility in residential, day and other support service regulations, and
- Adopting short and long range plans with specific milestones.

Although not initiated at the state mental retardation/developmental disabilities agency level, the following example highlights how a private organization orchestrated a focused, deliberate, and effective strategy aimed at eliminating its state's waiting list for residential services.

- **A Unique Advocacy and Collaboration Effort**

The Arc of New Jersey developed a "Key of Our Own" campaign that focused on the 4,000 individuals with mental retardation waiting for community residential services in their state. The authors of this campaign note, *"our first step was to make an agreement with the New Jersey Division of Developmental Disabilities (DDD) in which they would mail a joint letter from their Director and the Arc of New Jersey President to every family on the waiting list. In the letter families were asked to join the "Key of Our Own" campaign by returning an enclosed postcard that would place them on a special mailing list. They would then receive action alerts and publications telling them what they could do to help..."* (The Arc of New Jersey, A Key of Our Own Campaign, 1994).

Twelve hundred postcards were returned as of June 16, 1994. The Arc has since created a variety of publications to keep this issue in the public's attention and was able to convince the legislature to propose a \$160 million bond issue to construct and develop community living alternatives (primarily group homes and supervised apartments) for individuals waiting for services. The legislation was recently approved by the Legislature's Appropriations Committee and Signed by Governor Christine Whitman. The bond act was approved by the voters in November's elections.

Testimony of Robert Gettings, Executive Director, National Association of State Directors of Developmental Disabilities Services

Mr. Gettings summarized how states have responded to their growing service waiting lists by highlighting both near-term and longer term strategies they are employing.

● Near-Term Strategies

States that have enjoyed the most success in responding to the backlog in unmet services needs have used a combination of the following strategies:

- Qualifying for the maximum level of federal financial assistance through the Medicaid home and community-based (HCB) waiver program,
- Structuring their waiver program in ways to enhance the cost effectiveness of community services, and
- Reinvesting state/local dollars that are freed up as a result of new federal financial assistance in initiatives aimed at reducing the community waiting lists.

As noted by Mr. Gettings, Massachusetts has done a remarkable job in increasing the number of participants in the State's waiver program and currently ranks fifth among all the states in terms of the actual number of MR/DD waiver participants. He stresses, *"by [this] measure, the Commonwealth appears to be taking advantage of the opportunities to maximize federal funding for community based mental retardation services through the Medicaid waiver program."*

The other two near-term strategies suggest that the Commonwealth could develop increased activities in these areas.

● Restructuring Medicaid Waiver Programs

Unlike the ICF/MR program, the Medicaid HCB waiver allows states to *"reshape their approaches to organizing, financing and delivering community MR/DD services...to [meet] their own unique situation and needs."* Mr. Gettings stresses

that *"the type of program restructuring I'm referring to reaches beyond the addition of new service categories (e.g., supported living; supported work, etc.); instead, a growing number of states (e.g., Colorado, Missouri, Pennsylvania, Oregon, etc.) have fundamentally realigned their waiver programs (including payment methodologies and provider incentives) to allow support services to serve as a full-fledged alternative to traditional congregate services."*

- **A Reinvestment Strategy**

Mr. Gettings highlights an all too familiar problem that Massachusetts' officials have experienced, that is, *"hanging on to state dollars that are freed up as a result of accessing additional federal Medicaid payments."* He goes on to stress, however, *"for this reason, a strong case needs to be made for including service expansion as an integral part of a state's overall HCB waiver strategy before the state qualifies for and receives additional federal Medicaid payments...if it is not possible to retain control of all state revenue savings, it definitely is worth fighting to earmark 50 cents (or even 25 cents) on the dollar for MR/DD service expansion."*

He also makes an important observation regarding how such a strategy is implemented: *"Success almost always hinges on a coalition of consumers, providers, and state officials working together to convince budget officials and legislators of the wisdom of investing scarce fiscal resources in reducing services lists."*

- **Longer Term Strategies**

States should also consider additional steps once the short-term strategies are fully operational. Mr. Gettings outlined three longer range activities:

- Unifying responsibility and accountability for managing community mental retardation services,
- Revising and simplifying the State's approach to paying for community mental retardation services, and
- Continuing to expand the use of HCB waiver financing in ways that yield additional waiting list reductions.

As he indicated in his testimony, Massachusetts has taken several key steps to consolidate responsibility for administering the waiver program, among other activities directed at clarifying accountability for community services. There are other steps, however, that the Commonwealth could consider as part of the remaining two long range strategies.

- **Revising and Simplifying the Payment for Community Services**

Some specific steps that Mr. Gettings noted included the following:

- Increasing the use of an array of flexible, consumer/family managed services,
- Promoting greater competition among community mental retardation vendors by introducing market-oriented contracting rules and incentives for establishing new provider agencies,
- Developing a capitated payment system that is consistently applied across program categories, based on an individualized assessment of consumer needs,
- Creating a centrally managed pool of dollars to meet the needs of consumers/families who have extraordinary service/support needs.

- **Continuing to Expand the Use of HCB Waiver Financing**

Mr. Gettings stresses that the *"experience of other states tends to demonstrate that it is difficult enough to launch waiting list reduction initiatives but even harder to sustain them over time. For this reason, it is very important that the State's MR waiver program be managed consistently and aggressively including being alert [to] future opportunities to qualify for caseload increases."*

Finally, since so much of a State's effort relies on federal Medicaid payments to fund community mental retardation services, Mr. Gettings indicated that some of the above changes will be difficult to accomplish fully without violating federal Medicaid policies. As such, he suggests that Massachusetts officials consider preparing and submitting to the Health Care Financing Administration (HCFA) a research and demonstration proposal, under Section

1115 of the Social Security Act, requesting authority to test out new methods of organizing, financing and delivering publicly-funded mental retardation services. He notes that most recently, the State of Rhode Island submitted a Section 1115 waiver request to restructure their entire developmental disabilities service delivery system. The Rhode Island CHOICES proposal would eliminate all existing Medicaid funding categories and create a single federal-state financing stream for MR/DD services. The responsibility for selecting services, supports and providers would shift to consumers and their families within the constraints of a seven-tiered capitated rate system.

Mr. Gettings concluded his testimony with some important observations. First, solutions to eliminating the waiting list are not likely to be found in "first generation approaches" to organizing, financing and delivering mental retardation services, that is, *"Comprehensive, facility-based, one-size fits all solutions to the enormously varied needs of persons with mental retardation are simply too expensive and too stultifying. Instead, we need...a system of personalized services and supports that are largely controlled by and responsive to the needs of consumers and their families."*

Secondly, these *"individually tailored services must be managed within a framework that is sensitive to the constraints on available public resources. Individualization cannot be equated with an open-ended commitment of federal and state dollars; otherwise public policy will remain trapped in the same box it is in today, where spiraling increases in the cost of serving existing program participants foreshortens opportunities for states and localities to address the needs of unserved and underserved populations."*

As illustrated by the findings of the Commission's survey of other states and Mr. Gettings testimony, waiting list issues are being addressed in many ways. It is evident that increasing federal revenues, primarily through the Medicaid HCB waiver, is a major strategy that many states are pursuing. At the same time, several states are seeking a clearer understanding of who is waiting for services and supports, what these individuals and their families need and want with respect to supports, and the costs of such options. By

further investigating the complexities of needs of persons with mental retardation and their families, resources can be more precisely targeted and planned for on both a short term and long term basis.

III. CHARACTERISTICS OF THE WAITING LIST IN MASSACHUSETTS

"We are facing a crisis in our ability to provide support for persons with mental retardation in the Commonwealth. We have to respond to this crisis proactively or else we'll only see a continuous rise in the waiting list."
Representative Jim Brett.

This section presents information on two critical issues:

- The procedures by which a person is assigned to a waiting list for residential or day services, and
 - The size and characteristics of people on official waiting lists for residential or day services in Massachusetts.
-
- **How does one become a statistic on the waiting list?**

"The waiting list is about people and families in serious need. It represents real people living with care givers who have been stretched to the limit." Philip Campbell, Commissioner, Massachusetts Department of Mental Retardation.

In Massachusetts, any resident who has mental retardation is potentially eligible for services from the Department of Mental Retardation. Application for services occurs through the local Area Office of the DMR and is managed by a Service Coordinator. The Service Coordinator collects preliminary information to determine eligibility and may present this information to an Eligibility Review Committee. An Individualized Service Plan is developed and if the services needed are currently available, the individual is provided the specific services required.

For some applicants, services may not be required immediately, and the provision of periodic case management services is considered appropriate. For these individuals, case management services consist of periodic interactions or reviews to ensure that the individual's situation has not changed dramatically and to provide other types of assistance that do not involve enrollment in formal day or residential programs. For individuals who are living with their parents, respite services or other types of family support services may be provided.

Some applicants may be determined to need a day program or a residential placement, or both. If this need is considered to exist currently or within one year from the time of enrollment in the system, and if there is no available program into which the individual can be enrolled, the individual's name is entered on the DMR's official waiting list for residential or day services (or both). Thus, inclusion on the waiting list is a result of an individual meeting five conditions:

1. To be a Massachusetts resident,
2. To have mental retardation,
3. To need either a day program or a residential program or both,
4. To require the day or residential service currently or within one year of application, and
5. To have a determination that the needed day or residential service is not available.

The DMR has a system of prioritizing the urgency of needs for citizens on the waiting list for day or residential services. The priority schema consists of five levels, ranging from 1 (most urgent need) to 5. Persons assigned to a priority 1 classification are those who are in a situation that is deemed threatening to their or other people's health or safety. These priority classifications are made at the area office level. At present, the centralized registry of information on persons on the waiting list statewide (maintained by the Central Office) does not distinguish individuals on the waiting list by priority of need classification.

At the area office, individuals who do not meet the five conditions enumerated earlier but who will need services in the future may be entered on an "unofficial" waiting list maintained by the area office. These individuals may include those who receive case management services and/or who receive family support services funded by the DMR.

As will be discussed shortly, in May 1994, there are 3,236 individuals who are "officially" on the DMR waiting list. These are individuals who are either unserved (in need of a day and/or residential services but receiving neither) or who are underserved (currently receiving a day and/or residential service which is considered inadequate for their needs). It is important to acknowledge, however, that the "official" count is accompanied by many shadows, that is, individuals who

have very poignant and real needs but who have not been assigned to the official wait list.

Among the "shadows" of the official waiting list are:

- Individuals living with their parents who receive respite services or other types of family supports,
- Individuals who receive periodic case management services but who are not enrolled in formal day and/or residential programs,
- Individuals who do not meet the conditions for the waiting list but who are known to have service needs that will become imperative in the future (i.e., in greater than one year's time), and
- Individuals who have not yet applied for services from the DMR but who are known informally to DMR staff in the area offices.

Not surprisingly, estimates of the size of the "shadow" groups are imprecise. According to the DMR, it is estimated that there are about 1,000 individuals who are known to the staff of area offices, who receive either case management or some sort of family support services, and who will need either day and/or residential services at some future time. There are no reliable estimates or "guestimates" of the size of this unknown group of individuals.

There is a general perception that the factors differentiating those who are assigned to the "official" waiting list and those who are not assigned but known to area office staff lack precision. Clearly, a great deal of discretion is allocated to area office staff in their determination of priority of need and of whether the individual's need for services should be met within the next twelve months. These realities make reports of the "official " numbers of people on the DMR waiting list somewhat suspect, and probably represent an underestimate of the true need in the Commonwealth.

An important resource for understanding the size and complexity of the waiting list are the vignettes provided by many of the Regional Offices of the DMR which maintain more personalized information about individuals in need of services. The stories are, in many instances, deeply disturbing. There are innumerable accounts of individuals for whom there is a dire need of residential

services, but for whom there is a multi-year wait against a backdrop of serious behavioral alteration, and in some cases, physical danger. By any account or vantage point, these official and unofficial waiting lists contain gripping evidence of the huge waste of human hope and potential.

- **Characteristics of the Waiting List as of May, 1994**

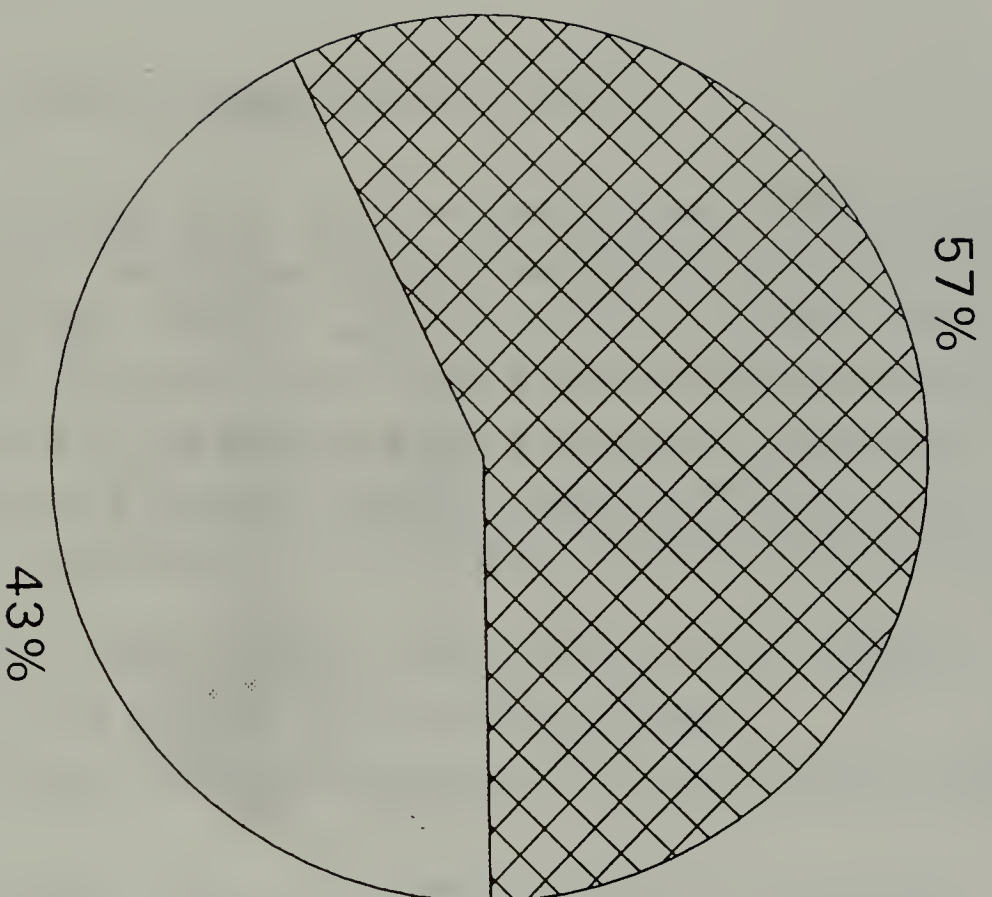
As of May 1994, there are approximately 22,000 people receiving services from the Department of Mental Retardation. Apart from the 22,000 individuals, there are approximately 1,087 who are designated as "underserved" and included on the official waiting list for services maintained by DMR. The designation of underserved is reserved for those individuals whose current residential and/or day services are considered unsatisfactory or incomplete.

In addition to the 22,000 served individuals, there are approximately 2,149 individuals who are entered on the DMR waiting list and who currently receive no services despite being deemed eligible for services.

Thus, the official waiting list of 3,236 individuals in May, 1994 includes two groups: those unserved (about 66% of the waiting list) and those underserved (about 34% of the waiting list).

What do we know about the characteristics of those on the waiting list? First, we know that 43% of those individuals on the waiting list are members of the "Turning 22" population (see Figure 1) and 57% are individuals otherwise living in the community. The "Turning 22" population consists of individuals who are graduating or have graduated from special education and who need services from the DMR in their adulthood. Through the provisions of Chapter 688, these individuals may have received transitional planning services to assist their move from special education services to DMR services, but are not now the beneficiaries of that planning.

Figure 1
Composition of the Waiting List as of May, 1994



☒ Community Based
 ☐ "Turning 22"

NOTES:

Source: Department of Mental Retardation

Includes both served & underserved on W/L

Second, we know that one-third of the individuals on the waiting list (both the unserved and underserved) are either living with elderly care givers, defined as age 60 or over (26%), or are individuals with mental retardation who are age 60 or over (7%) (see Figure 2). Thus, age-related issues are dominant within the waiting list population.

Third, we know that for both the unserved and the underserved, the predominant need is for residential services (71% and 57% respectively). Among the underserved group, about 15% are in need of both day and residential services, while among the unserved group, about 12% need a similar intensity of services (see Figure 3).

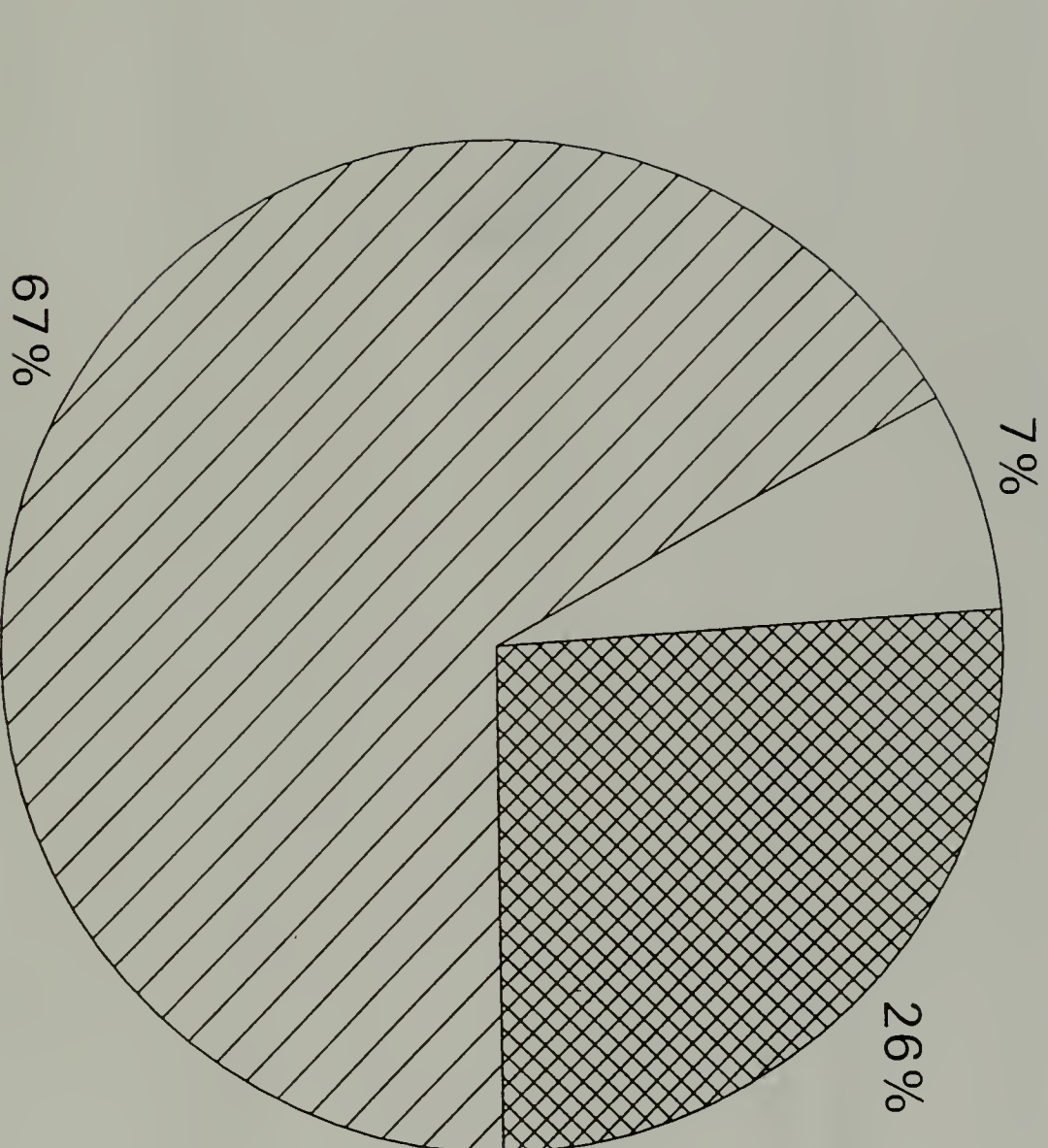
● **Analysis of Trends in the Waiting List Over Time**




The challenge of the waiting list is not a new phenomenon. There has been a steady, inexorable increase in the number of unserved persons on the official waiting list since at least October 1991 (the earliest point at which data used for this analysis was available). As illustrated in Figure 4, between October 1991 and August 1994, there has been a 36.3% increase in the total number of unserved individuals on the waiting list. While there has been a steady decrease in the annual rate of growth, the overall upward trend remains relentless. Specifically,

- Between October 1991 and September 1992, there was a 22.4% increase in the total number of unserved individuals.
- Between September 1992 and September 1993, there was an 18.0% increase.
- Between September 1993 and August 1994, the rate of increase slowed to 8.6%.

Figure 4 also portrays the annual increases based on needed services. As shown, the trend line for residential services mirrors the trend line for increases in the total number of unserved individuals. The rate of increase for those needing both residential and day services is steady, but at a less dramatic annual increase. Interestingly, there has been a decrease during the last year in the number of unserved individuals on the waiting list in need of only day services.

Figure 2
Age Related Factors Among the Population on the
Waiting List as of May, 1994



 Caregivers Aged 60 +
  Consumers Aged 60 +
  Other

NOTES:

Source: Department of Mental Retardation
 Includes both served & underserved on W/L

Figure 3
Service Needs of the Unserved and Underserved
on the Waiting List as of May, 1994



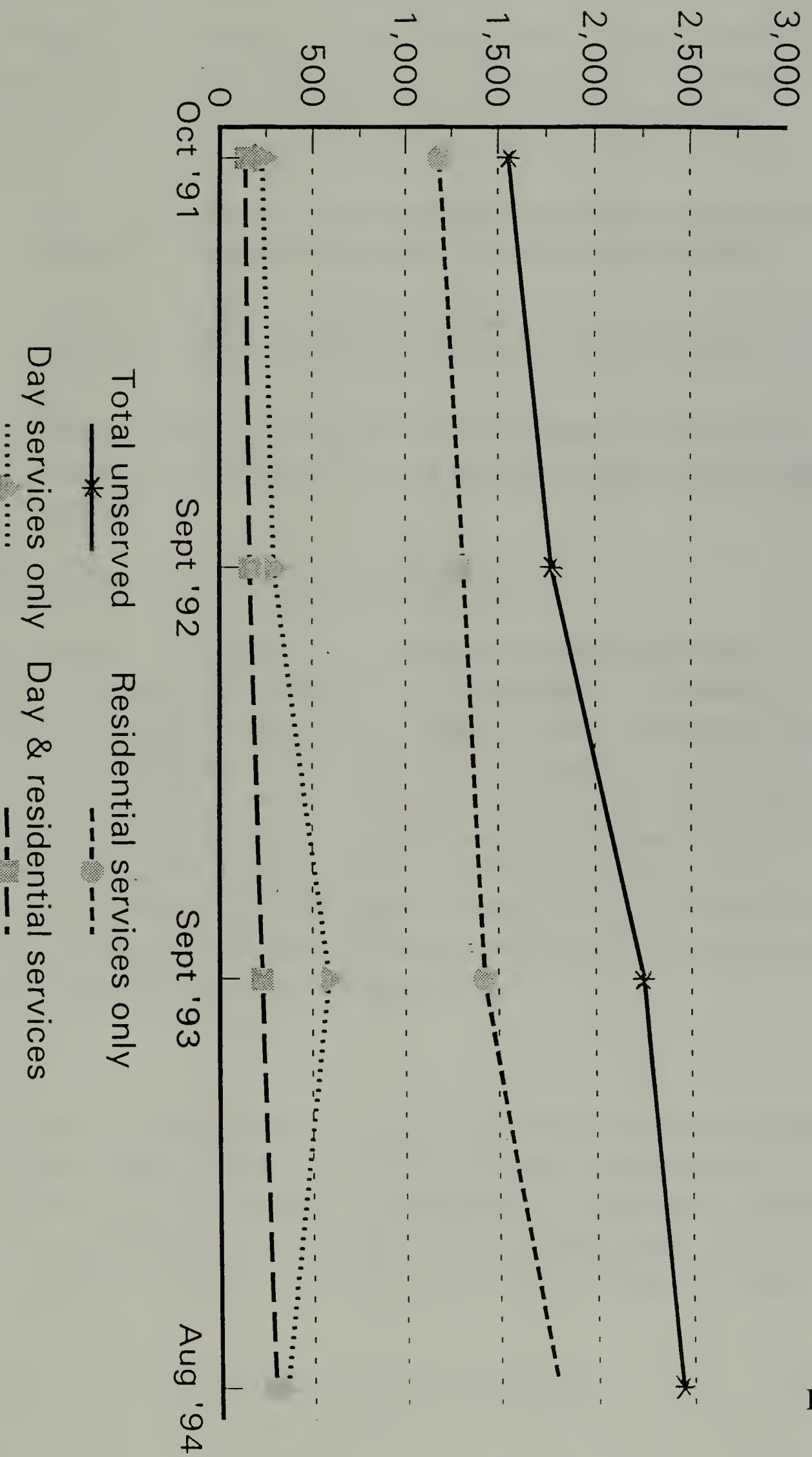
 Residential Services
  Day Services
  Both

NOTE:

Source: Department of Mental Retardation

Figure 4

Number & Service Needs of Unserved Persons on the Waiting List from October '91 - August '94



NOTES:

Source: Department of Mental Retardation
Includes only unserved persons on waiting list

Data were also available on the changes between July 1992 and August 1994 with respect to the number of people who are unserved and on the waiting list according to three critical characteristics: those who are in the Turning 22 designation, those whose care providers are aged 60 and over, and those consumers who are themselves aged 60 and over. Our analyses reveal that:

- There has been a 39.2% increase in the number of the unserved Turning 22 population during this time period (see Figure 5).
- There has been a 51.1% increase in the number of the unserved population whose primary care givers are age 60 or over (see Figure 6).
- There has been a 131% increase in the number of the unserved population of consumers who are themselves age 60 or over (see Figure 7).

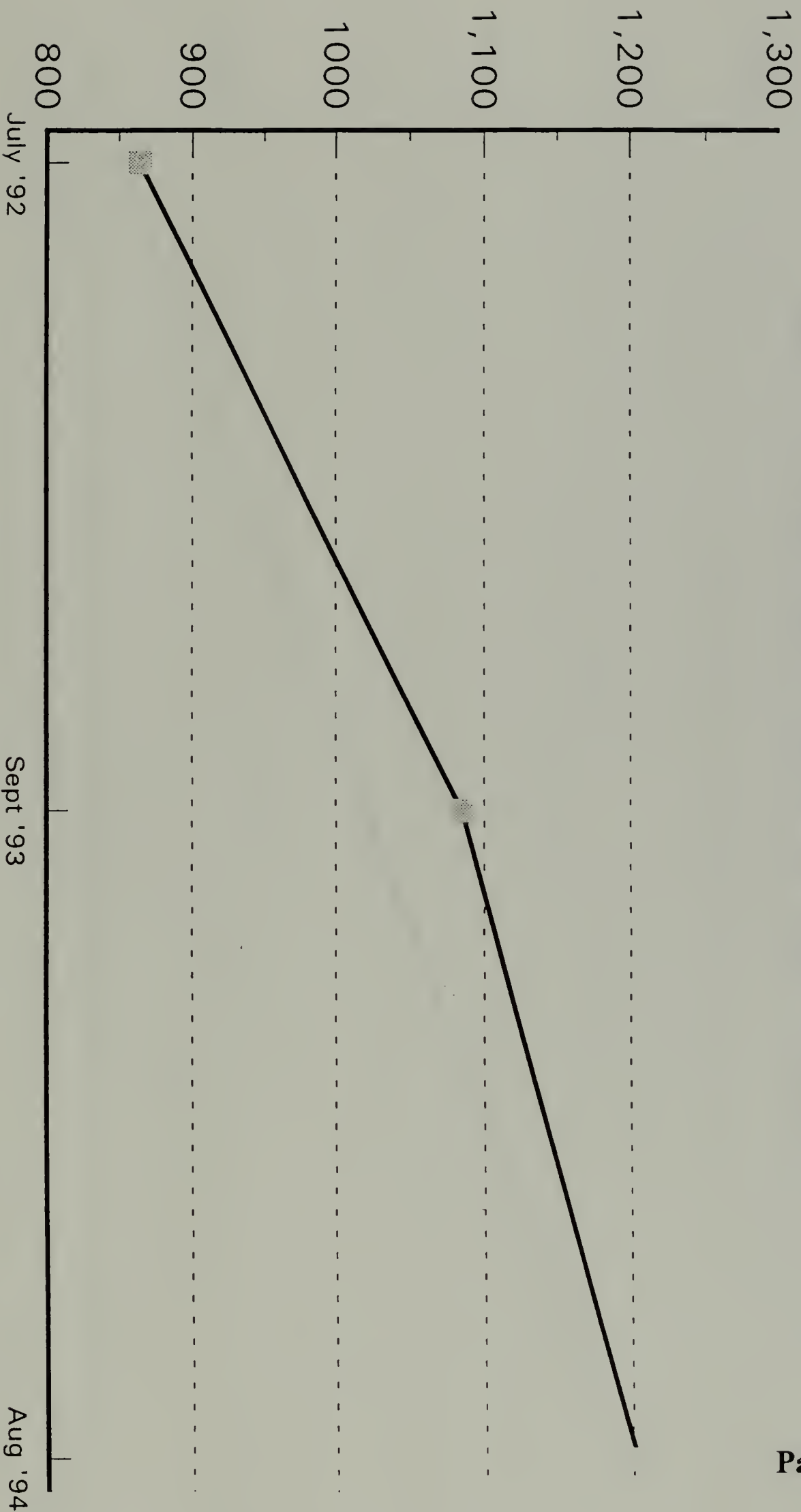
● **What We Don't Know About the Waiting List**

The information maintained by the Central Office of DMR on the characteristics of those on the waiting list is not extensive. It is not possible to describe the percentage of those on the waiting list who are considered Priority 1 cases (i.e., those in the greatest need of services), the functional, behavioral, or social characteristics of those on the waiting list, or the length of time that each individual has been on the waiting list. Along with other pertinent information, these types of data would be essential for a more detailed analysis of the individuals on the waiting list. Such analyses could yield more precise and valid information necessary for both short and long-term planning (with respect to needed service development, fiscal resources, etc.).

Summary

The sheer size of the current waiting list is grounds for immediate concern. As we have noted, many of those on the waiting list are themselves older, have older care givers, or are in the midst of a critical transition from special education services to the adult services system. Many others are individuals who live in a variety of community settings. Collectively, these are individuals for whom

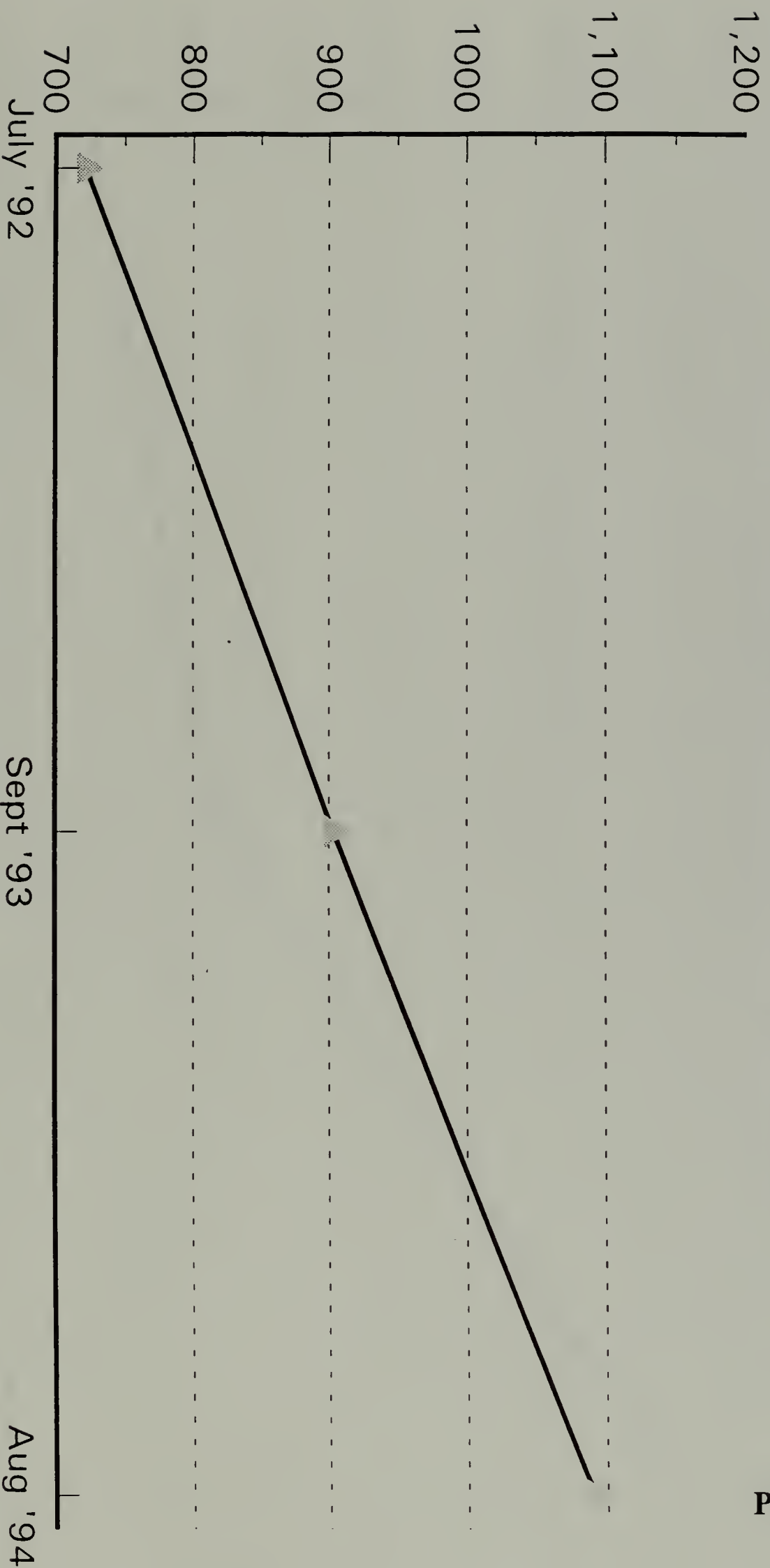
Figure 5
Increases in the Unserved Turning 22
on the Waiting List



NOTES:

Source: Department of Mental Retardation

Figure 6
Increases in Population of Persons w/Caregivers
Aged 60 + Among the Unserved on the Waiting List

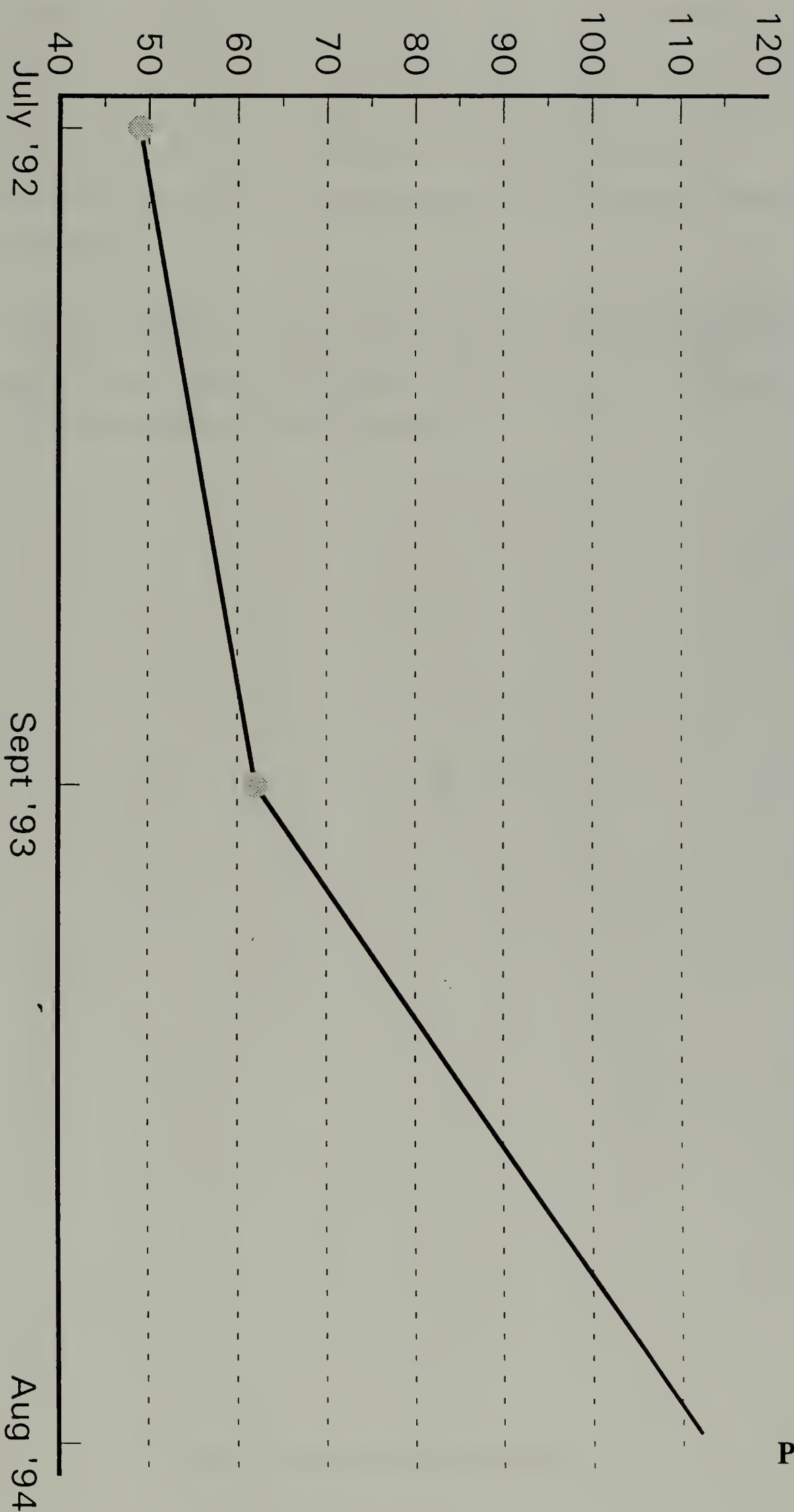


NOTES:

Source: Department of Mental Retardation



Figure 7
Increases in the Population of Consumers
Aged 60 + Among the Unserved on the Waiting List



NOTES:

Source: Department of Mental Retardation

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access to the system has been thwarted, despite their deemed eligibility for services. The gravity of their individual situations is well known at the local area office level and is suggested by some of the information maintained on the statewide population at the Central Office. It is also well known to the thousands of families, service providers, and advocates who must cope with the consequences of a service system that does not have the resources to meet the needs of its constituency.

At the Public Hearing, we heard testimony from many individuals and we subsequently received written testimony from many more. Their testimonies provide both analysis and pleas about the waiting list. In the next section, the basic themes of these testimonials are presented.

IV. STRATEGIES FOR ELIMINATING THE WAITING LIST: A REVIEW OF TESTIMONIALS TO THE GOVERNOR'S COMMISSION ON MENTAL RETARDATION

This next section of the report describes four major themes that were identified during the public hearing and focuses on the testimony delivered by parents, advocates, professionals, providers and consumers. This testimony provides compelling evidence for the need for changes in the Commonwealth's capacity to address the growing concerns of the "waiting list" population.

The four main themes discussed at the hearings and presented in written testimony include:

- Strengthen the Commitment to and Support of Families
- Restructure and Reallocate Resources/Equity in Service Eligibility
- Encourage and Promote Innovation in Program Design
- Enact Statutory, Regulatory and Policy Changes

● Strengthen the Commitment to and Support of Families

Many articulated a need to develop partnerships with families, particularly with families who are not looking to the DMR to provide 100% of their loved one's needs. Some families expressed a different vision of what the DMR's role is, namely, to support natural care giving of families through the provision of ancillary, but critical services. We also heard many poignant descriptions by families of how difficult their situations are and the need for DMR to divert/devote resources in their direction.

"We are a group of ladies in their seventies who have these older retarded children who lived at home all their lives. And now there is no future for them. All we know is that there are waiting lists. I need the Commission to create some change. No more talk!" Clara DeLeo, parent, Greater Waltham Arc.

"My strategy to reduce the waiting list is a pretty simple one, that is, at least in the future, is to help me keep my son off it. I want my son to avoid that damn list. And the best way that you can help me help him to avoid that list is to

increase, not decrease, family supports." Elaine Cockroft, parent, Arc of Massachusetts.

"I don't want pity. I want acceptance for what he is. I want a chance for him to live in a society, not to just live for mom and dad, have a life with friends and the support he needs to do this. More people have to be informed. Community living works. They are all responsible not just the parents." Evelyn Richard, parent.

Families and individuals who have had the benefits of early intervention, special education and school to work transition programs expressed different expectations, primarily in the form of increased supports in their own communities and options that are not readily available from the existing service menu.

"If I had one wish, it would be for support, emotional, financial, and hands on support. My goal for Tim is to have him be an active contributing person in the community, but we'll need support to help him make my wish come true." Jane Goff, parent.

"One of the things that is happening with families that I would encourage you to look at is, what kind of family support services are available now. What can we do to keep families intact and to make a commitment to make sure that families exist now whose children aren't going to be going into state schools as they might have in the past, they can live in their communities and be integrated into their communities." David Specht, Community Resources for People with Autism.

"Develop more family support services. While the value of these services is painfully obvious, money seems to go to programs and buildings. Family support options should provide families with choices for obtaining the resources and supports that will enable them to maintain a functioning family system that can nurture and provide for the needs of all family members including the family member with a disability." Michael Ripple, Executive Director of UCPA of MetroBoston.

"It is especially troublesome that the state dictates to families but does not include family concerns in the ISP." MaryAnn Dillon, parent.

"Do what the Commonwealth has always said it does, take care of its citizens, starting with those most in need. Recognize that families cherish their members." Dolores McLaughlin, parent, Arc of Massachusetts.

Supports and services that assist families during periods of short-term crisis, subsidies that help families meet the extraordinary expenses of care for a member with mental retardation at home and respite which allows families to take a break from the ongoing responsibilities of caring for a family member with a disability are a few options that were discussed in the hearing.

"One of the ways that services can be provided in a very flexible family driven, family directed, family focused way is through cash assistance." Leslie Kinney, Arc of Franklin County.

"It is time to support families and individuals with disabilities in ways they define so that they can live their lives in their communities with dignity." Emily Murgo, Families Organizing for Change.

"We believe that services should be individualized to reflect the unique needs, wishes and values of each consumer and family and that this process happens best when consumers and families participate actively in the process." Gordon Wise, parent.

Several noted the difficulty of establishing working partnerships between DMR and families who want to contribute financial resources or real estate so that their family members may remain in their family homes with needed supports.

"There are upper middle income families, as we've heard tonight, who have a lot of resources that they are willing to offer privately." Jody Williams, Executive Director of Massachusetts Developmental Disabilities Council (MDDC).

"One of the things that frustrates parents is hearing that the placements that they're looking for, or that DMR offers them, might be \$70,000 or \$100,000 placements. One family would just like an au pair to live with them at a cost of \$10,000-\$20,000. What they're being told by DMR is \$100,000 placement is what can be offered, but they have to wait for that." Leslie Kinney, Arc of Franklin County.

"I am the parent of identical twin sons with mental retardation 24 years of age. Almost two years ago my husband and I proposed our dream to the Department. We offered to give our home, mortgage free with the understanding that our sons would remain there as long as appropriate with necessary support. Rather than being excited at the possibility of a new venture reflecting private, community involvement our dream has from the start been regarded with caution. We have been told that there are no suitable consumers." Carol Beard, parent, Greater Boston Arc, NWW Committee.

- **Restructure and Reallocate Resources/Equity in Service Eligibility**

"Their lives are ticking, and I think we need to find a way to be as creative and innovative using existing money and new money to get the job done." John Britt, Executive Director, Massachusetts Hospital School.

Testimony was presented regarding the need for better use of existing resources, and for the need for equal access to the service system. Several people noted that DMR has been extremely successful in obtaining federal reimbursements for services under the Federal Home and Community Based Waiver program. It is anticipated that \$177 million additional dollars will come into the state under the Medicaid waiver by 1997. It was noted, however, that these new revenues now revert to the General Fund rather than to the Department. By reinvesting state savings based on federal reimbursements, one person noted that there could be a *"hell of a dent in our waiting list. I think the most significant contribution the Governor's Commission can make is to force a discussion on retained revenue. Mental Retardation is currently cleaning up the Boston Harbor."* Marylou Maloney, Regina Villa Associates.

"There are potentially some \$15,000,000 of Medicaid waiver money that can and should be allocated to residential placement for community families this year. We must not allow these Medicaid waiver dollars to filter out of DMR and into the General Fund." John Learnard, parent, Board member, Charles River Arc.

"Legislation should be enacted that will allow DMR to retain greater portions of revenues generated through federal programs like the Home and Community Based Waiver. It is very upsetting to constantly hear legislators say how DMR costs the Commonwealth 700 million a year, when they know this is not true. The reimbursement of a fair portion of the total line item, however, goes to the General Fund. As a society we have a moral obligation to care for persons that need help. It is a disgrace that we continue to have a system in place that is politically motivated and driven." Jon Johanson, parent, and Chair, DMR Statewide Advisory Council.

Others urged for more creativity and flexibility in the use of existing resources.

"To serve more people, new resources must be found, or the existing resources must be re-directed." Barry Schwartz, Vice President, Vinfen Corporation.

"I [do not] want prepackaged programs, but I want to care for individual's differences, not only for my kids but for anybody else's kids. That should be a hallmark." Bob Perry, parent.

"In Western Massachusetts, some families are beginning to directly control the funds and design day, work and in-home skills training programs for their family members rather than accept a slot in a predesigned site or model." Leslie Kinney, Arc of Franklin County.

"This testimony offers a strategy to begin the movement of a currently overburdened system of day and employment services to one which looks to utilizing on site supports to aid persons who are underserved into jobs and to advocate for the use of supported employment for those waiting for services

rather than electing a segregated option as a temporary holding area while other services are sought." William Kiernan, Institute for Community Inclusion.

A most troubling concern for families was the issue of equity.

"We were told if the institutions are closed we will use that money to serve all the folks who need services. That fact has proven to be untrue-that money has been taken from us. We have been cheated out of the promised increase in services. I was told that these actions would provide services for many who were currently unserved." Lucie Chansky, parent, Arc of Massachusetts.

Several noted the inequities of support between those living in the state's institutions and those individuals living at home or in community settings.

"Add my voice to those of many frustrated parents in Massachusetts whose "children" are growing older with little or nothing in the way of resources to help plan their futures...Because we choose not to institutionalize our child, the state saves money and then denies us resources when she reaches age 22." Bob Seay, parent, Cape Cod Arc.

"Having a child who is born handicapped in any way is a traumatic event in any family, but to continually battle for services is even more traumatic and adds even more of a burden...I hope you would look at the allocation procedure to be certain all clients are treated on an equal basis, regardless if they are cared for at home or in an institution." Herbert Elmer, Parents in Need.

"There are people who have 'Cadillac Services' and there are people with no services. Let's make sure everyone has a 'Chevy'. We need to insure that everyone receives quality service on an equal basis." Paul Merritt, Executive Director, Charles River Arc.

"Uphold the commitment to the community to equalize services for all. My son has been on a wait list for residential services for 14 years." Jean Walsh, parent, Greater Lowell DMR Advisory Board.

"I would ask that you support a 50/50 approach in terms of serving people so that for every person who is served from the institutions, one person waiting at home will also receive needed services." Carolyn Barrett, President, Arc of Massachusetts.

- **Encourage and Promote Innovation in Program Design**

"We will never be able to deliver all the services through DMR, but DMR can certainly facilitate the huge array of health and human services out there in the community. And we need to bridge that gap." Bonnie Gorman, Coalition for Children with Mental Retardation.

Considerable testimony was received on the need to access services provided by other agencies, which, in concert with DMR, would enable a broader range of options to be available to the consumers in need of services. Many noted that DMR needs to be proactive and aggressive in brokering its services along with services available from agencies such as Massachusetts Rehabilitation Commission, Department of Public Health and the Executive Office of Community and Development (EOCD) to the benefit of those in need.

"There needs to be some innovative partnerships between the Department of Social Services (DSS), the Department of Mental Retardation (DMR), the Department of Public Health (DPH), and the school systems to help some of these families." Leslie Kinney, Arc of Franklin County.

"All I know is that Jessica receives individualized services from different agencies funded through DMR and Massachusetts Rehabilitation. She receives Social Security funding, Medicaid funding for Personal Care Attendant (PCA) services and transportation from the Ride. Because of these services, she has a home life and I have a wonderful home life because of those services. I don't know how it can be done. I know it's the right thing to be done." Kris Caprani, Roommate.

Families indicated that intensive collaboration with the various agencies involved in developing services for this population is sorely needed. The state Department of Mental Retardation is clearly the lead agency for this population,

however, *all* human service government agencies have roles and responsibilities that need to be clearly articulated and implemented.

"Look for ways to promote constructive collaborations between providers to achieve economies of scale and quality improvements." Michael Ripple, Executive Director of UCPA of MetroBoston.

"It's a shame that we haven't yet succeeded in encouraging or forcing the Department of Mental Retardation to see itself as a facilitator, or collector of information, and a bringing together of people." Jody Williams, Executive Director of MDDC.

Personal care attendants (PCAs) are funded through the Medicaid Program. This service was frequently cited as a prime example of the need to develop interagency relationships that could assist many of those without any services who live at home.

"I am the parent of a severely multiply handicapped son who is 17 years old. My son could benefit from PCA services, which are very difficult to access. I would like to see a strategy involving a better way to work with Medicaid to access needed services and to work with the state to assist families who have insurance issues." Carol Tague, Executive Director of Greater Waltham Arc, testifying on behalf of Kathy Horrigan, parent.

Testimony was received from representatives of programs which represent the type of interagency collaboration so frequently cited as a critical strategy for enhancing service availability.

"Assistive technology can be utilized to assist in activities of daily living, to increase the independence of the individuals or to ease the transition and provide some support for caregivers. We are a federally funded project that can assist people of all ages with any kind of disability." Judy Brewer, Program Manager, Massachusetts Assistive Technology Partnership.

"The object of the P.A.S.S. Program [Plan for Achieving Self Support Program, funded by the Social Security Administration] is to serve as a work incentive to individuals who have disabilities and receive benefits from the Social Security Administration. It should be noted that the increase of 214 new P.A.S.S. plans represents \$875,688.00 in new funds generated for the state of Massachusetts in one year." Susan Buckley, Dr. Michael Slacheck, Staff Members of the P.A.S.S. Works Project.

"The Massachusetts Rehabilitation Commission has a housing registry of accessible housing. People with mental retardation who need accessible housing should have immediate access to that through computerized networks." Jody Williams, Executive Director, MDDC.

"I have spent the last 2 1/2 years assisting individuals with disabilities in accessing housing of their own choice. I did this with very little funding. I did this with mostly generic resources...I'd like to see a community housing development organization created for persons with disabilities so more access could be made for federal and HUD funding and home funding that comes through." Ann Lane, Independent Living Advisor, South Shore Arc.

The absence of a centralized housing policy has forced regions and areas across the Commonwealth to fend for themselves, thus creating fragmentation and philosophical confusion.

"Many in our area have given up on the state system, and are sometimes unaware of the options that exist." Deidre Johnson, parent, Minute Man Arc.

"First of all, the Commonwealth needs to make a commitment to the issues at hand. People need to be served. We on the Cape have seen too many situations that have become a crisis for people not getting services at home." Kent Killam, Cape Cod Organization for Rights of the Disabled.

The need for more aggressive development of accessible and affordable housing was expressed by many. It was noted that millions of dollars could be available from the Executive Office of Community and Development (EOCD) equity loan program when final regulations are promulgated. These funds would

provide equity loans to non-profit developers to provide community based housing for the Departments of Mental Health and Mental Retardation.

"Could DMR not provide a form of housing voucher or certificate to those who are denied by EOCD's homeless and at risk of being homeless regulations?" Anne Lane, Independent Living Advisor, South Shore Arc.

"Provide more flexible living arrangements for the large numbers who have the daily living skills to manage for themselves but need some supervision and apartments with drop-in supports for those who can largely function on their own." Polyxane Cobb, parent.

"Individuals who are older unserved or just unserved based on priority of need should qualify for partnership funds ranging from \$6,000-\$18,000 a year in situations where family members are willing to pay for the housing or a significant staffing portion of an individual's services." Representative Jim Brett, Legislator.

"One participant asked us to help her find a subsidized, barrier-free, two bedroom apartment where she would live with a local provider. Affordable/accessible housing which suits participants individual needs is mandatory." James Lyons, Jr., parent, Northeast Independent Living Program.

"It means that in fact the many service providers in the Commonwealth have to look at things differently, have to design and develop their programs in a different way." William Kiernan, Institute for Community Inclusion.

"When my daughter was 18 (she is now 28), and many times since, I have inquired about community residences for the future, particularly in light of my physical condition. The answer has always been the same...Priority #1 does not really mean much because there are just no residences available. It is sad to think the only opportunity for a community residence would be if both my husband and I passed away. It shouldn't be this way." Arlene Penza, parent.

- **Statutory, Regulatory and Policy Changes**

"The role of state government is to ensure that structures are in place that facilitate partnerships among the various state government agencies to accomplish (a) good policy development and streamlined consumer-responsive administration and (b) simple, easy access by consumers to both 'soft services' such as information and referral and to hard services." Jody Williams, Executive Director, MDDC.

This theme focuses on the need to support new legislative initiatives designed to provide greater options for service recipients. Specific testimony noted the value of proposed legislation entitled "An Act to Support Citizens with Disabilities and Their Families" which has been filed in each of the last three years. It was noted that this bill has been scrutinized by various fiscal, legal and administrative bureaus within the Commonwealth's legislative branch, but has not received necessary leadership or momentum to secure its passage.

"A large number of us have decided we need to have our voices heard. We are proactively seeking to create change." Emily Murgo, parent, Massachusetts Families Organizing for Change.

"The Family Support Bill would help families have some say in policy making and make a difference to those of us whose voice is so hard to hear as we struggle to do everything and be a family." Donna Kulpa, parent.

"This bill would require state human service agencies to develop a plan to organize their agency's existing resources to meet the needs of people with disabilities and their families in their homes and communities. This is one cost effective way of addressing needs of the thousands of consumers on waiting lists." Representative Paul Kollios, Legislator.

It was also noted that state policy makers need to implement federal requirements to develop policies and plans that will expand service opportunities for all constituencies. In particular, the Americans with Disabilities Act was cited as a powerful tool for widening the life chances and circumstances for people with disabilities.

"It is critical to work with public officials to implement and enforce the Americans with Disabilities Act and other federal policies at the local, state and national levels to assure full opportunities for early intervention, education and employment of persons with disabilities." Michael Ripple, Executive Director, UCPA of MetroBoston.

Finally, some participants at the public hearing focused on the need for planning, based on acquisition and analysis of valid data.

"Basic to the process of developing services for those on the waiting list is a decent plan based on real needs." Carolyn Barrett, President, Arc of Massachusetts.

"Increased funding is not the only way we can attempt to alleviate the problems that the waiting list is creating. I offered an amendment to the FY '95 state budget that would direct the Commissioner of DMR to develop a plan to address the needs of people waiting for services. The plan would address the current and anticipated categories: residential, work and training, transportation and family support." Representative Paul Kollios, Legislator.

"I called the Department to find out if the Department had a five, ten or 15 year plan after privatization. I didn't get a response. So that tells me there was nothing. I needed the information because I'm going into Boston, and I'm talking to the legislators." Richard Faucher, Lowell Arc Board.

"A great abandonment has become public policy. There is a retreat from service from the very agencies that were created to serve." Polyxane Cobb, parent.

Testimony suggested that all individuals will benefit from a planning process to ensure that essential needs -- such as a place to live and opportunities to work -- will be met.

V. RECOMMENDATIONS

The expanding waiting list demands immediate action. No single solution will suffice. Rather, we recommend a multi-faceted set of activities that will reduce and ultimately eliminate the waiting list. While it may be argued that existing resources could be used more efficiently to serve greater numbers of individuals, the sheer size of the waiting list suggest that one strategy alone will not significantly reduce or eliminate the waiting list. No single agency or individual can "solve" the waiting list problem. Concerted action by the legislature, various public agencies, private advocacy organizations, and the citizens of the Commonwealth is needed. But, with a multi-level effort, a commander-in-chief is also needed. We view the Commissioner of the Department of Mental Retardation [DMR] (or the Commissioner's designate) as the appropriate leader. The Commissioner's effectiveness depends, however, upon his/her ability to win the commitment and earnest efforts of other agencies and individuals.

Our specific recommendations are as follows:

1. **Develop a strategic plan** to reduce the number of people on the waiting list by a significant amount (e.g., 25 % of the total or 50% of those who are consumers age 60 and over, or 100% of those who need both day and residential services, etc.) within a specific time period (e.g., one year). Multi-year projections of reductions in the waiting list should be made until the waiting list is greatly minimized.
2. **Enact legislation** to ensure that the DMR base budget is linked to the amount of federal revenues secured through the Title XIX Home and Community Based Waiver Program. Other recommendations are fruitless unless there is a clear strategy for the expansion of the DMR base budget to increase access to services.
3. **Create a Family-to-Family Chain** to connect families of individuals on the waiting list. The purpose of the chain is to promote intermediary helping strategies among those affected by the lack of access to services. Creative

strategies, based on families' experiences, could be publicized to support and sustain naturally occurring efforts at the grass roots level. Support for initiation of the Chain could be requested from the Massachusetts Developmental Disabilities Council.

REFERENCES

Alabama Department of Mental Health and Mental Retardation (1994). Five-year plan (FY '93-'94 and FY '97-'98). Birmingham: Division of Mental Retardation.

Colorado Developmental Disabilities Planning Council (1993). A study...Colorado's waiting list for developmental disabilities services. Arvada: Rocky Mountain Resource and Training Institute.

Connecticut Waiting List Planning Committee (1994). Planning report to eliminate the DMR waiting lists. Hartford: Department of Mental Retardation.

Davis, S. (1987). A national status report on waiting lists of people with mental retardation for community services. Arlington, TX: Association for Retarded Citizens of the United States.

Florida Department of Health and Rehabilitative Services (1994). Living everyday lives: Update - strategic plan for individuals who have developmental disabilities (1994-1996). Tallahassee: Developmental Services.

Hayden, M.F. (1992). Adults with mental retardation and other developmental disabilities waiting for community-based services in the U.S. *Policy Research Brief*, 4(3), 1-16. Minneapolis: University of Minnesota, Research and Training Center on Residential Services and Community Living, Institute on Community Integration.

Kansas MH/RS, Department of Social and Rehabilitation Services (1993). A preliminary report on Kansans who are mentally retarded or otherwise developmentally disabled waiting for community services. Topeka: Division of Mental Retardation/Developmental Disabilities.

Mangan, T., Blake, E.M., Prouty, R.W., & Lakin, K.C. (1994). Residential

services for persons with mental retardation and related conditions: Status and trends through 1993. Minneapolis: Research and Training Center on Residential Services and Community Living, Institute on Community Integration, University of Minnesota.

New Jersey, The Arc of New Jersey (1994). A Key of Our Own Campaign, Trenton.

New York Office of Mental Retardation and Developmental Disabilities (1993). The community challenge: NY DD plan 1990-1995, executive summary. Albany: OMR/DD.

Smull, M. (1989). Crisis in the community. Baltimore: University of Maryland at Baltimore. Department of Pediatrics, School of Medicine, Applied Research and Evaluation Unit.

